The AIDS Project Newsletter, Vol.2, No.3 (May 1989)

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The AIDS Project

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You’ve probably read the statistics. More than 50,000 people have already been killed by the AIDS virus in the United States alone, a figure exceeding the number of American lives claimed by the Vietnam war. Over 90,000 people are suffering at present, and another two million, as yet without symptoms, are thought to be carrying the AIDS virus. There is no cure in sight.

Statistics, however, do little to convey the human tragedy behind the numbers—the suffering of those with HIV infection, or the grief of the loved ones they leave behind. Statistics don’t tell the stories of the twelve year old boy from Lewiston, the prisoner from Windham, the father of two from Presque Isle or the pastry chef from Portland, whose deaths are among the more than 50 counted here in Maine.

It’s for them, their families, and, sadly, the more deaths to come, that we’re bringing the Names Project Memorial Quilt to Portland. We need your support.

WHAT IS THE NAMES PROJECT MEMORIAL QUILT?

The Names Project Quilt began in San Francisco about three years ago when a handful of people got together to make sure the names of those who had died from AIDS would not be forgotten. Friends, family members, co-workers, and lovers began sewing 3’x 6’ quilt panels—the size of a grave—as a personal way to express their love and to channel their grief over lives lost to AIDS. Word of their efforts travelled quickly and they were soon receiving panels from all 50 states.

To their pleased surprise, the project struck a chord nationally and internationally. Only three years later, the Quilt has grown to over 8,000 names and commemorative panels. Millions have viewed the Quilt, or read about it, or seen it on TV. Most astounding of all is the incredible power and emotion embodied in the Quilt with the simplicity of its very human message. It has united literally millions of people in the spirit of life, sharing and compassion.

SEE IT AND UNDERSTAND.

This Memorial Day weekend exhibit in Portland will mark the Quilt’s only appearance in the Northeast this year. Thousands are expected to travel to view it. Every New England state will be bringing yet more panels to add to the Memorial. Over two dozen new Maine panels will be displayed along with over 800 from the National Memorial Quilt, which has grown too large to exhibit in its entirety in virtually any indoor location.

HOW CAN YOU HELP?

We hope you will make a point of visiting the Quilt during the four and one-half days it will be on display in Portland. We ask your help to make this project a success. Pennies, quarters or dollars—anything you can spare. Every Penny Counts toward helping the fight against AIDS in Maine. Your pocket change and penny jars will pay for the cost of bringing the Quilt to Maine. Every penny raised over the amount we need to exhibit the Quilt will go to provide direct services to People Living With AIDS in Maine.

We can’t do it without you. The Quilt brings us a message of love. Won’t you share your love with us?
Executive Director’s Message
by Robert Mitchell

Just a few months ago, a Portland newspaper published a front page article declaring that the number of new cases of AIDS had crested in Maine. Citing Bureau of Health statistics, the article left the casual reader with the impression that the AIDS epidemic is under control in our State. More recently, a weekly publication featured an article which profiled the diligence of Maine physicians providing medical care to People With AIDS. While this article warned that the present level of medical resources would soon be unable to keep up with the increasing number of AIDS cases, it also left the casual reader with the sense that the hard work of dedicated people would keep the AIDS epidemic under control. To the public-at-large, the message has been simple: All is well; All is under control.

The Maine Health Foundation’s recent announcement about reductions in funding for the Financial Assistance Fund is a harsh reminder to everyone that all is not well; all is not under control with AIDS in Maine. In fact, the challenge of AIDS has never been greater or more difficult in every aspect. A few examples:

- The rapidly growing numbers of People With AIDS in need of financial assistance has quickly overtaken the fund raising achievements of the Maine Health Foundation. In just nine months, the financial requirements of this program have risen from $2,400.00 to $10,000.00 per month.

- In the face of State and Federal cutbacks in AIDS related funding, The AIDS Project and other service providers in Maine are struggling to raise vitally needed funds for AIDS education and support services. Without additional financial support, The AIDS Project and other service providers may in the future be forced to reduce services at a time when the need is growing at an unprecedented pace.

- Contrary to the media coverage about a cresting of new AIDS cases, there were nearly as many new cases of AIDS reported in the first three months of 1989 as there were in all of 1988. AIDS service providers are hard pressed to meet their rising staffing and budget needs as the number of cases grows.

- AIDS activists and service providers are appealing to the legislature for adequate financial support for existing AIDS education and support service programs. Without legislative intervention, existing programs will receive less public funding in 1989 than in 1988. Public support was not adequate to meet current needs in 1988, and several important community programs do not presently receive any State funding at all.

- With strained human and financial resources, service providers are continually in greater and greater need of volunteers to help provide essential services to People With AIDS. Many step forward; more are needed.

- The PWA Coalition of Maine, an organization dedicated to the self-empowerment of People With AIDS, struggles from month to month for its financial survival.

All is not well; all is not under control. And, it’s not a pretty picture for the future. While it is true there have been wonderful accomplishments, it is equally true the struggle to meet the challenge of AIDS has only begun.

What can we do? What can you do? What can be done is whatever you can do comfortably. Write to your legislators and voice your opinion on AIDS legislation. Financially support AIDS programs and service providers. Volunteer to help. What you do can and will make a difference.

Acupuncture and AIDS Workshop

For our 3rd Sunday Workshop Series in May, Sheldon Ganberg, D.Ac. will present a workshop on the uses of Acupuncture and Chinese medicine in the treatment of AIDS. Sheldon is the Director of the Acupuncture Health Care center in Portland where there are currently 8 PWA’s undergoing acupuncture treatment. If you are interested in learning more about acupuncture as a treatment option, the workshop will be held Sunday, May 21st from 1:00-3:00 P.M. at The AIDS Project.

The AIDS Project is a not-for-profit organization dedicated to providing and promoting services to people with AIDS and AIDS related illnesses, advocacy regarding AIDS related issues and concerns, and AIDS related health education and information to the citizens of Maine.
Financial Fund In Crisis

As many of you know, the Maine Health Foundation, Inc. (MHF, Inc.), a primary funder of projects relating to Maine lesbian's and gay men's health concerns, maintains a modest Financial Assistance Fund, currently channeled through the three regional case management agencies (The AIDS Project [TAP], Dayspring, and Eastern Maine AIDS Network [EMAN]). Each agency reports monthly on those individuals helped by the Fund. No names are reported to MHF, Inc. Each month, the Trustees of MHF, Inc. review the reports of the total amount of money drawn from the fund, and, periodically, each of the case management agencies, anticipating future need, is required to submit a request for additional funds.

The Financial Assistance Fund, which provides small sums to Persons With AIDS, is in no danger of collapse, but it is in crisis. The amount of money is limited, and the great increase in demand for funds has created a serious problem. There simply isn't enough money to meet current demands; every day more people are asking for money from the Fund. We believe it's important for you to know the situation, what MHF, Inc. is trying to do about it, and how everyone can help.

First, some background. The Financial Assistance Fund is the formal result of a concern first expressed by Maine Health Foundation, Inc., in 1983, a full year before anyone in Maine had been diagnosed with AIDS. That was the year MHF, Inc. was founded, and in that year it raised about $1,300, all of it going to AIDS related work. MHF, Inc. took on, as its primary task, the job of raising money to help people in Maine affected by AIDS. That meant money to educate the public and ourselves, money to start up projects which local, state and federal governments would not be willing to pay for, and money for both the special emergency needs and "quality-of-life" needs of people with AIDS. That first $1,300 created the Gay Health Action Committee (now called The AIDS Project) and brought to Maine the first mass distribution of brochures on AIDS.

Since its beginning, less than six years ago, MHF, Inc. has aggressively solicited money from individuals, groups, institutions, and from the state itself, primarily to support AIDS related concerns. In 1984-85, the MHF, Inc. budget was $2,600; in 1987-88, nearly $50,000. But, no matter how fast we've worked, and no matter how hard we've tried, the need has outpaced our ability to come up with money.

The current situation: When the Financial Assistance Fund was established, it became MHF, Inc.'s number one priority. We did not forget our other concerns (both AIDS and non-AIDS related), but we were determined to make Maine people with AIDS our first concern. The Financial Assistance Fund was to be a "quality of life" fund - something found in very few states in this nation. MHF, Inc. agreed that it was important to help PWA's maintain as high a standard of living as possible, and that the Financial Assistance Fund should be thought of, not as a welfare fund (which ought to be a public responsibility), but as a small fund for PWA's to draw upon when other channels had been exhausted.

But, that's not the way the fund is being used. Here are the figures. In July, 1988, MHF, Inc. projected that it would have to raise at least $50,000 before June 30, 1989, just to meet the needs of the Financial Assistance Fund. That amount was more than all moneys raised in the previous year, and, it did not take into account MHF, Inc.'s other goals.

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Update: FDA Drug Approval Process
By Paul Corser and N. Patrick Hennessey, M.D. (reprinted with permission from Gay Men's Health Crisis (GMHC) of New York)

The system of testing and licensing drugs in the United States is one of the most rigorous-and slow-in the world. A close look at the Food and Drug Administration (FDA) will point out the reasons for this lengthy procedure, and also some areas of unnecessary delay.

A potential new drug first undergoes extensive laboratory evaluation to determine its physical properties, biological activity, and some measure of its safety in human cells or tissues. Testing then moves into animal models, where the emphasis is on safety, toxicity, and approximate dose of the drug.

At this point, the drug's sponsor, usually a pharmaceutical company, must submit an Investigational New Drug (IND) application to the FDA. This application includes the complete composition, the manufacturing process, and the results of all preclinical testing. The IND application must contain a detailed outline of the proposed human studies (protocol) of the drug. The IND becomes effective 30 days after submission if the FDA does not object.

Once an IND becomes effective, the drug moves into Phase I clinical trials, which involve small numbers of patients and are designed primarily to determine the maximum safe dose, the optimal schedule and route of administration, and the manner in which the drug is absorbed into and eliminated from the body. In most cases, Phase I trials can be completed in one year or less.

If a drug is proved safe, without serious side effects, Phase II trials begin. These trials, also termed efficacy studies, take place in much larger groups of patients (200-300), all at a similar stage of their disease. These trials are frequently controlled with the use of an inactive substance (placebo) in a portion of the patients being studied. Neither the patient nor the researchers know who is receiving the drug or who is receiving the placebo until the end of the study. When the study is over, the two groups of patients are compared for disappearance or progression of the disease, cure, or in serious disorders, death. The study must enroll sufficient numbers of patients so that differences in the treatment groups are recognizable.

If the safety profile of the drug determined in the Phase I trial is confirmed, and the drug shows sufficient benefit, the drug will move into Phase III trials. These studies, which use very large groups of patients, are often placebo controlled and can last up to 2-3 years. They are intended to confirm the effectiveness of the drug and uncover low-incidence side effects.

Once the Phase III trials have been completed, the sponsor may file a New Drug Application (NDA) with the FDA, which contains thousands of pages of data from all aspects of the drug's studies to date. It can take the FDA several years to analyze the data and make a decision on the NDA, though in some cases the FDA can shorten this time period, as in the case of AZT (Retrovir) in which the NDA was approved in a record 107 days.

This lengthy approval process is justified for several reasons. The approval of a drug which is not safe, or whose benefits do not outweigh the potential toxicities, does a great disservice to the population, as does the approval of a drug which is safe, but not effective. What is not justified in the approval process is the undue lag in developing protocols and evaluating drugs for use in humans for serious diseases such as HIV infection.

The FDA has made several promising moves in the development and timely review of HIV-related drugs. The treatment IND regulation has made the drug Ganciclovir (DHPG) available to patients with CMV infection, and trimetrexate available to patients with PCP. The FDA recently announced that it will allow PWAs to bring limited supplies of unapproved drugs into the country for their own personal use. Both of these rulings are positive moves, but more is needed.

The recent FDA approval of dextran sulfate trials sponsored by the National Institute of Allergy and Infectious Diseases (NIAID) illustrates the shortcomings of this system. Dextran sulfate was studied in a Phase I trial that was completed in November, 1987. According to FDA guidelines stated earlier in this article, Phase II studies begin upon successful completion of Phase I trials. As of late July, 1988, Phase II studies of dextran sulfate have not begun.

When Dr. Anthony Fauci, head of the AIDS trials program at NIAID, was asked why the Federal government had failed to follow its own policy for the evaluation of HIV-related drugs, he stated that "staff shortages" and unspecified "technical problems" were to blame. Yet FDA Commissioner Frank Young states that evaluation of HIV-related drugs is now the highest priority.

If you believe that safe and effective drugs are among your rights as a citizen, then it is your responsibility to ensure that the system established for providing such drug works.

Tell Dr. Anthony Fauci and Dr. Frank Young how you feel about your right to safe and effective drugs. Tell them how it affects your life and the lives of those around you. If you don't tell them nobody will.

Frank E. Young, MD
Commissioner
Food and Drug Administration
5600 Fishers Lane
Rockville, MD 20852

Anthony Fauci, MD
National Institute of Allergy and Infectious Diseases
National Institutes of Health
Building 31, Room 7A-03
Bethesda, MD 20205

FOR CLIENTS OF THE AIDS PROJECT

Lunch At The Lounge
Tuesdays and Thursdays
12:00 - 1:30 P.M.
Tuesday-Vegetarian
Thursdays-Traditional Fare
Financial Fund In Crisis
continued from page 3

or any other AIDS-related projects. Now, with a quarter of
the fiscal year left to go, MHF, Inc. has already raised over
$73,200 for the Financial Assistance Fund. The largest per­
centage of the money has gone to help pay rent. More than
50 clients a month now ask for help. Last July, MHF, Inc.
had to raise $2,400 to maintain the Fund for clients served by
TAP for a month. Last month it had to raise $10,000 to
maintain the Fund for the clients of TAP, Dayspring and
EMAN.

While MHF, Inc. did not intend it to be so, and even
though the case management agencies (like TAP) have
screened applicants for special need, the Financial Assist­
tance Fund is perceived in the minds of some to be a welfare
fund. Some have come to depend on it for monthly assis­
tance.

Recently, TAP and other agencies were forced, regretable­
ably with little notice, to inform their clients that the Finan­
cial Assistance Fund was no longer able to fully meet the
great demand. MHF, Inc.’s recent AIDS Benefit Ball did not
meet projected goals. But, even if it had, the demands upon
the Financial Assistance Fund have made it impossible to
meet every need. Some requests will have to be denied. The
fact is that in Maine there are now more people with AIDS
asking for help from the Maine Health Foundation Finan­
cial Assistance Fund than there is money to go around. That
situation is not likely to change in the near future.

MHF, Inc. continues to solicit funds - and help in raising
those funds - and it is pledged to support the Financial
Assistance Fund. But its funds are limited, and it does not
have the power to force people to give. The Trustees of
MHF, Inc. are fifteen volunteers, none of them paid, elected
to three year terms, each personally committed to raising the
money needed to keep the Financial Assistance Fund afloat.
We are doing our level best to do so.

The larger question, and one which we cannot
address here, is about the welfare system and
why money intended by MHF, Inc. to enhance
quality of life must be used, instead, for basic
welfare.

Maine Health Foundation, Inc., solicits,
especially from people with AIDS and those
who care about them, contributions in the
forms of money, ideas and energy, in the ongo­ing
effort to maintain the Financial Assistance
Fund. Contributions, in the name of the Fi­
nancial Assistance Fund, may be mailed to:

THE MAINE HEALTH FOUNDATION, INC.
P.O. BOX 7329 DTS
PORTLAND, MAINE 04112

Federal AIDS Info Service Is Open
NASW NEWS, February 1989

Data on 5,000 AIDS-related programs and 2,000 pieces
of AIDS educational material became available in late 1988
through the National AIDS Information Clearinghouse.

NASW Health/Mental Health Commission staffer Verne
Lyons and representatives of other organizations concerned
with AIDS were present last December at the opening of the
clearinghouse, which is sponsored by the federal Centers for
Disease Control.

Its purpose is to help health care professionals and AIDS
program coordinators locate hard-to-find educational ma­
terials and facilities and services for AIDS patients. A team
of information specialists, some of whom are bilingual, use
on-line computer databases and other resources to respond
to both phoned and written requests.

The clearinghouse also distributes U.S. Public Health
Service publications about AIDS, answers inquiries about
resources for educating the public and makes referrals to
other information sources. A telephone service is operated
by information specialists.

Plans call for the clearinghouse to begin operating an
electronic bulletin board for CDC and state AIDS coordina­
tors, publishing a newsletter and assisting state public health
programs.

The National AIDS Information Clearinghouse can be
reached by phoning (301) 762-5111 Monday through Fri­
day, 9 a.m. to 7 p.m. (Eastern time), or by writing: NAIC, Box
6003, Rockville, MD 20850.

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MONDAY

AIDS Response of the Seacoast in Portsmouth, NH, runs a support group for PWA's and PWARC's and HIV+'s. The group is open to people from York County. A holistic healing model is used incorporating meditation, visualization, heart centering, music and touch in a supportive and loving environment. For more information and an intake interview, contact Suzanne Bowman at (207) 439-2136 or Peter Welch at (603) 436-5115.

Waterville Support Group for PWA's, PWARC's and HIV+'s and their families, friends and caregivers. Meets from 6:30-8:00 P.M. at St. Mark's Episcopal Church, Waterville. For more information call Dan Gardiner at 873-3904.

Support Group for PWA's, families, friends and significant others, every other Monday at Miles Conference Center, Damariscotta, 6:00-7:00 P.M. Contact Kandy Powell at 563-1709. Sponsored by AIDS Coalition for Lincoln County.

A Support Group for persons with AIDS, ARC and HIV infection meets in Auburn at the First Universalist Church. Meetings are the 2nd and 4th Monday from 1:00 to 3:30 p.m. in the Church Library. Call Tim Sutter (626-3435) or Cecilia Leland (289-5060) for more information.

TUESDAY

Morning Support for PWA's, PWARC's, HIV+'s, their families, friends, and caregivers meets from 10:30-12:00 Noon. Location: The AIDS Project, 22 Monument Square, 5th Floor, Portland. Call 774-6877 or 1-800-851-2437 for more details.

Evening Support Group for lovers, friends, caregivers and family members only. Meets from 7:00-8:30 P.M. at 29 Cushman Street, Portland. Call Brooke Alexander at 772-1678 for details.

Merry Meeting AIDS Support Services (MASS) A support group for families, partners & friends of persons with AIDS and HIV disease. Meets the 2nd and 4th Tuesday of each month at 7:00-8:30 P.M. at Parkview Hospital Library in Brunswick. Contact Cecilia Leland at 725-4955 for more information.

ACT-UP Boston meets every week at 7:30 P.M. Call (617) 49ACTUP (492-2887) for more information. ACT-UP: AIDS COALITION TO UNLEASH POWER -- United in anger and committed to direct action to end the AIDS crisis.

AIDS-Line Staff Meeting at 6:00 P.M. the first Tuesday of each month. Location: The AIDS Project, 22 Monument Square, 5th Floor, Portland.

Downeast AIDS Network (DEAN) holds a support group for people affected by AIDS every Tuesday evening at 7:00 P.M. in Ellsworth. Call 326-8580 for the location.

AIDS Education & Support Group for Knox County, P.O. Box 1613, Rockland, Maine 04841. Public meeting are held at 7:00 P.M. on the 2nd Tuesday of each month at the University of Maine Augusta Thomaston Center. For more information call 354-6906 or 596-6979 or write.

Support Group for Parents and Friends of Lesbians and Gays meets the 4th Tuesday of each month at the Pilgrim House, 9 Cleveland Street, Brunswick. Call 729-9843 for more information.

WEDNESDAY

Positively Sober Group, AA-AIDS-related meeting from 6:00-7:00 P.M. at The AIDS Project, 22 Monument Square, 5th Floor, Portland. Meeting is open to all PWA's, PWARC's and HIV+'s in recovery from substance abuse.

THURSDAY

Women's AIDS, ARC & HIV+ support group. The group meets 10:30-12:00 at the AIDS Project, 22 Monument Square, 5th Floor, Portland. Facilitated by Diane Elze and Jan Carter. This group is for Women with AIDS, ARC or HIV+ only. Call 74-6877 or 1-800-851-2437 for more information.

AIDS Coalition of Lincoln County is a group focusing on AIDS education in Maine. We welcome PWA's, PWARC's, HIV+'s and their lovers, friends and family members, as well as all concerned people to our meetings. For time and place, call Barbara Brampton at 563-3032.

AIDS Support in Waldo County. A group of people affected by AIDS and part of the AIDS Education Committee of Waldo County. More information can be obtained by calling 338-3736, Monday-Thursday, 9:00 A.M. to 4:30 P.M.
Ongoing Calendar of Meetings

OTHER (continued)

Support Group for persons with AIDS, ARC and HIV+, and their family members, friends and caregivers. The group meets every Friday, 7:30-9:30 P.M. at Portsmouth Hospital, Classroom 1 and 2.

Out-of-State Services/Hotlines

NH-AIDS Info Line:
(603) 224-3341
(800) 752-AIDS (24 hr. Hotline)

VT- AIDS Info Line:
(802) 254-4444
(800) 882-2437 (VT Only)

Mass.-AIDS Info Line:
(617) 536-7733
(800) 235-2331 (MA Only)

Special Calendar of Events

The Names Project Maine will be at the Bangor Mall on May 11, 12 & 13 displaying a portion of the AIDS Memorial Quilt in memory of those who have died of AIDS in Maine. Hours will be from 9:30 A.M. to 9:00 P.M. For more information please call 774-2198.

Open Heart Productions will have a fund raising dance for The National AIDS Memorial Quilt, Saturday, May 20, 8:00-12:00 P.M. at The Peoples Building 155 Brackett Street, Portland, $5.00 donation requested. Call 774-2087 for more information.

AIDS Response of the Seacoast of Portsmouth, NH will be holding buddy training sessions on May 12, 13 & 14 and May 19, 20, 21. For more information please call (603) 433-5377 or write: AIDS Response of the Seacoast, P.O. Box 3188, Portsmouth, NH 03801.

The AIDS Project Wish List
If you can help us with these items, please call us at:
774-6877

Air Conditioners
Bookcases (for offices and reception area)
Coat Rack
Records
Books
Games
Cassette Recorder
6 Burner Electric Stove
Industrial Dishwasher
IBM Compatible Wordprocessing System with Printer
Typewriters
Photocopier
Telephone System
Pots and Pans

Two Ways You Can Help Us Help Others

A General Donation

The AIDS Project relies on the support of its friends to provide services and to provide educational programs. Contributions to support our programs are welcome.

Name:
Address:

City: State: Zip:

Donation: $15 $25 $100 other $

A Memorial Contribution

To express condolences for the loss of loved ones, many friends choose to make a memorial gift to The AIDS Project. A letter will be sent to notify a surviving loved one or friend of your gift.

Name:
Address:
City: State: Zip:

Donation $ In Memory Of:

SUBSCRIBE

This Newsletter relies on subscriptions to exist. We are grateful to those who have subscribed, and to those who have not, please do so now. Rates: Individuals $10/Low Income $5/Institutions $30/PWA's Free. Please make your check payable to: The AIDS Project, 22 Monument Square, Fifth Floor Portland, Me 04101. Thank You.

Name:
Address:
City: State: Zip: